

Final Report 2015



Maine Developmental
Disabilities Council

SUPPORTS & SERVICES FOR OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES AND DEMENTIA IN MAINE

As life expectancy has increased for individuals with developmental disabilities so has the risk for developing age related health conditions, including Alzheimer's disease and related dementias, taxing states capacity to serve this growing population and the unique challenges they face in accessing dementia-capable programs and services. This report assesses the current status of Maine services for aging adults with developmental disabilities and dementia and makes recommendations for future actions.

This study was completed by Dementia Care Strategies.

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Dementia Care Strategies would like to thank the Maine Developmental Disabilities Council staff for their assistance and the Stakeholder Group for their insights.

The Maine Developmental Disabilities Council is authorized and funded via the Developmental Disabilities Assistance and Bill of Rights Act of 2000. It is governed through a partnership of individuals with developmental disabilities, family members and representatives from agencies and organizations who receive funding on behalf of persons with developmental disabilities. It is responsible for developing and implementing a statewide plan to address relevant priority areas through a variety of systemic change, capacity building, and advocacy activities.

The mission of the Maine Developmental Disabilities Council is to ensure that individuals with developmental disabilities and their families participate in the design of, and have access to, needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration, and inclusion in all facets of family and community life. The Council has a vision that all people are included, supported, and valued in communities that offer them opportunities to participate and succeed as they choose.

The Maine Developmental Disabilities Council commissioned this study to assist in the development of community-based services for older adults with developmental disabilities and dementia as well as to contribute to Maine policy and research on this population in the state's framework on aging.

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Executive Summary

Across the nation, communities and service systems are beginning to notice and address the needs of persons with developmental disabilities and dementia. In the 1930s, the mean age at death for people with developmental disabilities was about 19 years. By the 1990's that had increased to 66 years and has continued to rise to over 70 years. The number of adults with developmental disabilities age 60 years and older is projected to nearly double from 641,860 in 2000 to 1.2 million by 2030. Because people are living longer, families have a longer period of care giving responsibility. In Maine it is estimated that approximately 4,350 persons with Intellectual Developmental Disabilities are living at home with caregivers who are over the age of 60.

Our current system of services for persons with developmental disabilities was conceptualized in the 1970s and 1980s, a time when there were very few elderly and limited capacity to address specific needs related to aging. While most of this population experiences aging in much the same way as do persons with typical development, there may be differences related to prior function or specific diagnosis. An important difference is that there is little awareness of issues related to aging which is of particular concern as it relates to dementia.

As the nation's oldest state, Maine has taken planning for aging very seriously through efforts such as the Maine Aging Initiative. A 2013 study by the Rand Corporation found that dementia is more costly to the nation than either heart disease or cancer. The greatest economic cost of dementia is associated with providing institutional and home-based long-term care rather than medical services. In the general population, Medicaid spending is 19 times higher for individuals with dementia than per person spending for all others. Dementia will therefore increase the already significant costs related to caring for individuals with developmental disabilities.

The prevalence of developmental disability is commonly accepted to be between 1.5% and 2.5% of the general population. Between 19,900 and 33,200 individuals of all ages in Maine are estimated to have an intellectual or developmental disability, of whom perhaps a fifth receive Adult Developmental Services. Maine has long demonstrated a high level of commitment to providing services to these persons. Persons with Down syndrome develop dementia early and often: 25% of individuals with Down syndrome over the age of 35 display the symptoms commonly associated with Alzheimer's disease. This increases with age, with an estimated 40% developing Alzheimer's disease by their 50's. The Maine Center for Disease Control estimated in 2009 that there were 12,891 Mainers of all ages with Down syndrome. Using national data to construct estimates, between 1,289 and 1,547 adults with Down syndrome are over the age of 40 and are likely to be high risk of developing Alzheimer's disease. Even a small number of individuals receiving Developmental Services with a diagnosis of dementia has the potential for enormous impact in terms of resource utilization. This group also has a disproportionate impact on family caregivers, usually parents, who may experience aging related issues at the same time.

Planning for and delivery of aging and developmental disability services is largely separate. Developing a cross-systems initiative to increase access to appropriate and effective service supports for adults with developmental disabilities and dementia-related conditions is an important step towards a holistic system of care. The goal of this project is to identify ways of embedding evidence-based practice into the processes and structures of agencies and organizations responsible for care and service delivery that will result in improved use of resources and improved outcomes for those at risk for dementia, individuals living with dementia, and their caregivers.

In 2010, the Maine Developmental Disabilities Council identified dementia as an emerging concern. It commissioned this report intended to provide Maine families, service providers and policymakers with:

- An understanding of the current service needs of individuals with developmental disabilities and dementia;
- An identification of gaps between those service needs and current and future service availability;
- Recommendations that address the current and future service needs;
- An analysis of the best and promising practices in providing services and supports to older adults and their families;
- A review of current research, government policies, services and supports, including natural and funded services and supports; and
- Identification of areas of current and potential alignment, integration and collaboration of supports and services provided by community-based aging services and community-based developmental disability service providers.

This report also identifies specific recommendations for further action intended to address the needs to:

- Increase awareness of dementia and developmental disabilities for the general public, state agency personnel, elected representatives, developmental disability providers, health and long term care professionals and among persons with developmental disabilities and their families.
- Integrate services and supports through partnerships with Maine's aging networks.
- Expand systemic capacity through workforce development, implementation of evidence based screening and intervention, enhanced family support services, and development of best practices.
- Adopt evidence-based dementia screening.
- Improve data for planning and administration of high quality, evidence-based services and supports.

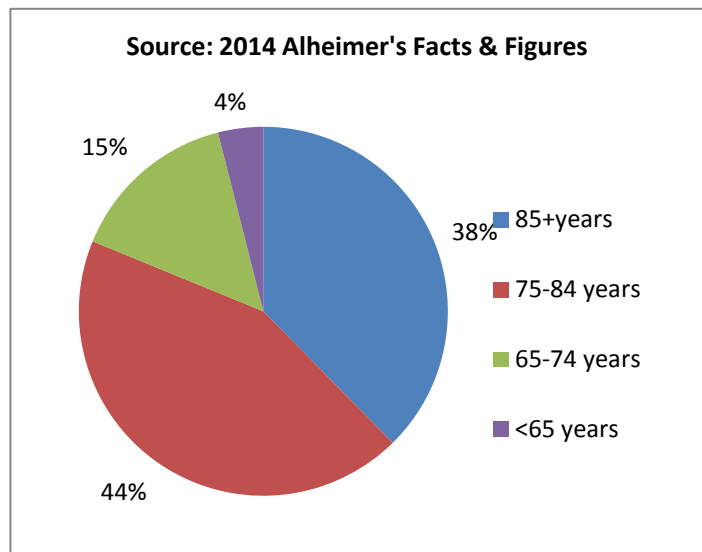
I. Demographics

Over the next 20 years the number of older adults with developmental disabilities and older family caregivers will increase considerably. The prevalence of dementia is also expected to increase significantly as the population of older adults with developmental disabilities increases. This is a particular concern for Maine where more than 21% of the population will be over the age of 65 by 2020.

Dementia is a general term referring to a group of symptoms. Memory loss (especially for recent events), impairment in executive functioning (a set of mental functions that control judgment, insight, emotional control, initiative, planning, organizing, etc.), loss of communication skills, and disorientation to time and place are the key features of the onset of dementia.

The term dementia is not a diagnosis. The syndrome of symptoms that we refer to as dementia can have many causes. Some, such as Alzheimer’s disease, vascular dementia, Lewy Body dementia, etc. are irreversible. Other causes of dementia may be treatable – including, but not limited to, hypothyroidism, medication interactions, malnutrition, dehydration, metabolic disorders, menopause, Lyme disease, and depression.

Age is the greatest risk factor for developing dementia. Alzheimer’s disease is the most common form of dementia: statistics suggest that 4% of the population under the age of 65, 15% of the population ages 65 – 74, 44% of the population ages 85 – 84, and 38% of the population aged 85+ have Alzheimer’s disease or a related dementia. Vascular dementia, caused by small strokes or transient ischemic attacks and Lewy body dementia (both Parkinson’s disease dementia and dementia with Lewy bodies) are the next most common.



Risk factors for dementia, other than age, are cardiovascular disease, diabetes, head trauma, smoking, alcohol use, obesity, and family history. Current thinking is that the majority of Alzheimer's disease occurs as a result of complex interactions among genes and other risk factors.

There are no projected or actual statistics or registries, at a state or national level, on the number of people with developmental disabilities who have dementia. Therefore, it is difficult to determine with any accuracy how many Mainers with developmental disabilities are living with or are at risk of developing some form of dementia. MaineCare records also do not accurately reflect the prevalence of dementia; in addition, there are many adults who may not be included in MaineCare statistics.

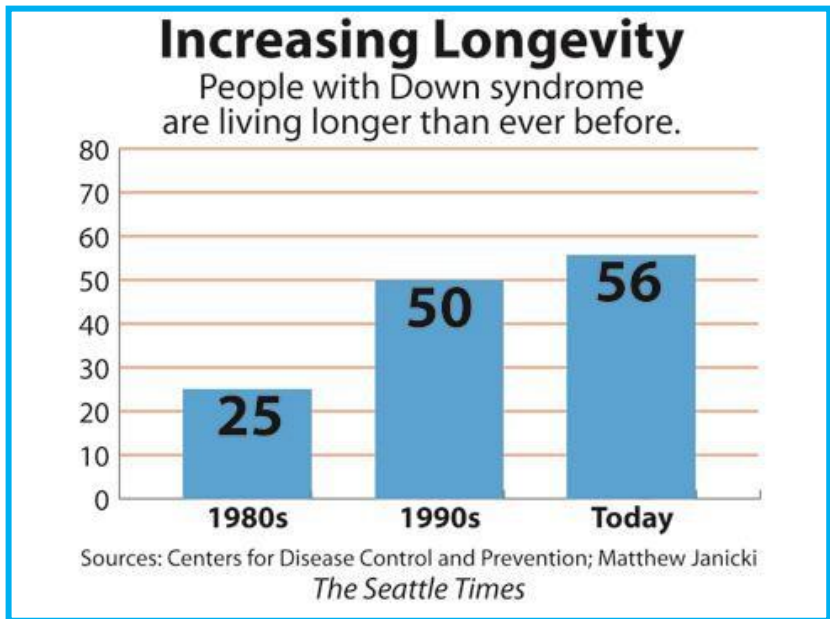
A “best guess” estimate can be made by applying national prevalence statistics to Maine’s population. The Arc of the US, the American Association on Intellectual and Developmental Disabilities, etc., tend to agree on a small range of percentages -- roughly 1.5% to 2.5% -- of the total general population as having a developmental disability. Applying this percentage to the number of persons of all ages in Maine (1,328,302 in 2013) would lead to an estimated 19,924 – 33,207 individuals of all ages in Maine with a developmental disability.

IT IS ESTIMATED THAT THERE ARE BETWEEN 19,924 AND 33,207 MAINERS OF ALL AGES WITH SOME FORM OF DEVELOPMENTAL DISABILITY.

Specific to individuals with developmental disabilities is the high rate of occurrence of Alzheimer’s in individuals with Down syndrome. By middle age, many people with Down syndrome develop the plaques and tangles in the brain that are associated with Alzheimer's disease. Studies suggest that more than 75 percent of those with Down syndrome aged 65 and older have Alzheimer's disease, nearly 6 times the overall prevalence.

Autopsy studies on adults with Down syndrome show that by age 40, the brains of almost all individuals have significant levels of plaques and tangles, abnormal protein deposits considered Alzheimer's hallmarks.

Despite the presence of these brain changes, not everyone with Down syndrome develops Alzheimer's symptoms. 25% of individuals with Down syndrome over the age of 35 display the symptoms commonly associated with Alzheimer’s disease. The percentage increases with age with an estimated 40% developing Alzheimer’s disease by their 50’s.



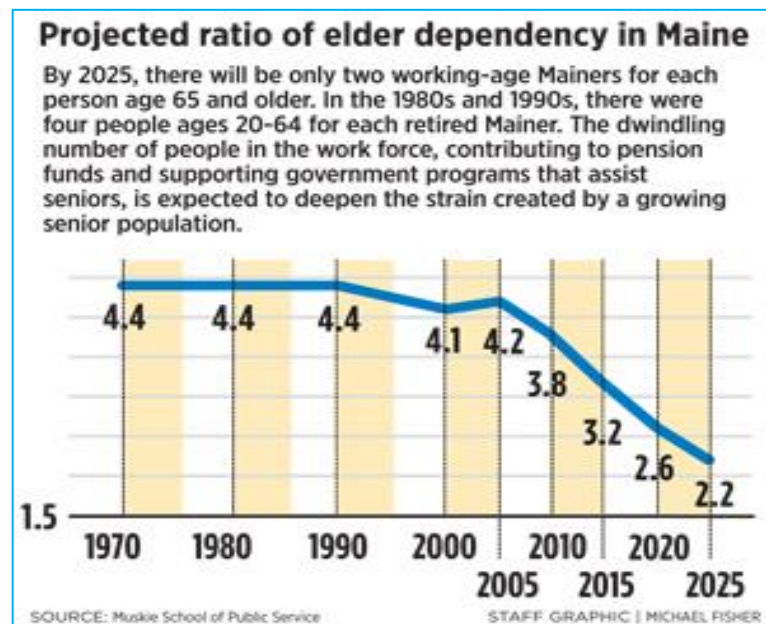
In 2009 it was estimated that there were 12,891 Mainers (of all ages) with Down syndrome. . National statistics suggest that 10 – 12% of adults with Down syndrome are over the age of 40. If we apply that percentage to Maine data it can be estimated that approximately 1,289 to 1,547 adults with Down syndrome specifically are over the age of 40. Therefore, a rough estimate would be that between 515 and 619 adults with Down syndrome either have Alzheimer’s disease currently or will develop Alzheimer’s disease at some point before the age of 60. There is no general agreement on when an adult “officially” enters old age. Most publicly supported programs assign the arbitrary age measure of 60 or 65 years as the point at which adults reach eligibility for “aging” or “elder” services. As with the general population, whose average lifespan has grown from 66 years in 1950 to 78 years in 2007, the life expectancy for adults with developmental disabilities has grown over the last few decades due to medical advances and improved living conditions. The life expectancy for people with developmental disabilities is more similar to that of the general population, with the mean age

at death ranging from the mid-50s (for those with more severe disabilities or Down syndrome) to the early 70s for adults with disabilities of other etiologies.

Nationally, over 75% of people with developmental disabilities live with families, and more than 25% of family care providers are over the age of 60. Another 38% are between 41-59 years. Most of these families receive few support services and face long residential services waiting lists.

Complicating the needs of aging adults generally is the shift in old versus young in Maine's population. Muskie School of Public Service Economist, Charles Colgan, has stated that by the end of 2020, those over age 65 will outnumber people aged 20 to 34 and below. That age bracket - 20 to 34 - is important, because that is the age people enter the workforce and replace those who are retiring. The impact of this shift will be profound – fewer workers to provide needed services, fewer taxpayers to support the provision of those services, and significantly higher demand for costly long term care services. The sharp rise of Maine's older population will mean that a higher percentage of Maine's state budget will need to be allocated to social services at the same time that there is a smaller tax base to pay for those services.

Maine will face a number of challenges to providing care for its expanding population of aging adults. It can be anticipated that the services that support aging Mainers will be overwhelmed. As a result, more focus will be placed on family supports – at exactly the same time that the aging family caregivers of adult children with developmental disabilities and dementia will be less capable of providing them.



II. Stakeholder Input

In May 2013 a collaborative training event regarding developmental disabilities and dementia took place: over 200 were in attendance, far more than had been anticipated, and participants articulated the need for further conversation about the topic. A stakeholder meeting was held in March 2014 to discuss the status of the care system and the needs of Mainers with developmental disabilities and dementia. The purpose of the meeting was to gather information from key informants and stakeholders about service gaps, barriers and needs. A wide range of organizations participated representing a broad spectrum of aging and developmental disability organizations and interests including, but not limited to:

- Community service providers of services
- Area Agencies on Aging
- Office of Aging and Disability Services
- Long Term Care Ombudsman
- Long term care facilities
- Alzheimer’s Association, Maine Chapter
- Visiting nurses
- Maine Guardianship Services
- University of Maine at Orono, Center for Community Inclusion
- Home care agencies

Kathryn Pears of Dementia Care Strategies, Inc. and Rachel Dyer of the Maine Developmental Disabilities Council shared background information on the project with the group.

Comments from participants included:

Challenges/Needs

- Lack of flexibility around funding and living arrangements.
- Guardianship, lack of future planning and person-centered planning.
- Staff training – needs to be more “intense” and ongoing (for example, 2x/year).
- How to identify early stages of dementia.
- Interventions to support individuals where they live.
- Ideas on how best to provide appropriate staff training and dementia-capable services when there are 3 individuals living in a home and only 1 has dementia.
- Philosophical shift in thinking required for staff: skill maintenance vs. skill development.
- Support needed for staff to deal when they see an individual starting to lose function.
- Support group for professional caregivers would be useful but it is difficult for staff to get paid time for training and support.

- Education and training in how to identify dementia earlier in the process.
- Ensure programs for the general population such as prevention, wellness, etc. are fully accessible.
- Education on how to deal with guardians who are in denial that a child or sibling has dementia.
- Need for more dementia-capable services for aging caregivers.
- Current waiting lists for publicly-funded community programs (multiple mentions).
- Educational opportunities for caregivers.
- Respite.
- Ways to reach aging parents who have an adult child who has never been “in the system.”
- Education on clinical aspects developmental disability and dementia – example: how to rule out causes of symptoms other than dementia.
- Need for immediate resources when caregivers “burnout” or become sick themselves and can no longer provide full-time care.
- Family ethic that caring for the individual is their responsibility – guilt at having to turn over what they perceive as their personal responsibility to someone else – belief that being in the state system is not a good thing (memories of Pineland) – fear of the system (will not get the services they really need and get something they do not want instead) – lack of awareness of what resources exist.
- More education for the medical community (multiple mentions).
- Stronger dementia component in Direct Support Professional training curriculum.
- Marketing campaign similar to Planned Parenthood and domestic violence – public service announcements, flyers in public restrooms.
- Need screening tool to identify early onset of dementia.
- Need information on resources available in physician’s offices.
- Concerted effort to develop and implement a long term plan (it was noted that this is a topic that has been discussed since the late 1990’s – “...implementation...not more talk.”)
- Physical environment accommodations and adaptations are difficult to provide in existing homes.
- Inflexible funding based on location of services.
- Training costs are part of regular Sec. 21 rate – rate cuts in prior years have made it difficult for providers to balance providing training versus other program and participant needs.
- Paying for more extensive training and paying staff for their time would require cuts elsewhere
- Staffing costs are increasing but rate has stayed the same.
- No long term planning (Roadmap for Change for Developmental Services only mentioned aging once).
- Difficulty integrating into traditional long term care.
- Lack of awareness of available resources for families.
- Transitioning clients – need to commit to aging in place.
- Difficult to reach family caregivers of individuals not in the system.

- Medical community does not understand developmental disabilities and dementia.
- Ways to support staff in understanding the philosophical shift in caring for a person dementia from rehabilitation to habilitation as well as emotional aspects of caregiving when client is losing function.
- Difficulty in adapting existing programs and housing to accommodate individuals with dementia throughout the course of the illness (increasing staff needs, programmatic changes, physical environment, etc.).
- Lack of a screening/assessment tool to identify early changes in functioning due to dementia.
- Insufficient training and emotional support for professional staff.
- Lack of awareness of guardianship process and the importance of future planning.
- Need to make more efficient use of funding already in place.

Opportunities

- Savvy Caregiver training will be offered to family caregivers.
- There are a number of resources already in place statewide. The problem is in how to coordinate them and make people aware of them.
- Intermediate Care Facility availability around the state for those needing 8 hours of professional nursing care for a profound nursing need. Physician assessment is needed for approval. Some of these facilities also offer day programming.
- Physician's offices could be a resource for outreach as they are caring for the aging caregiving parents.
- May need to consider a new residential model, i.e. specialized dementia homes.
- Revisit regulations to make it easier for people with dementia to access services.
- Many more resources now for aging adults (i.e. Aging and Disability Resource Centers)
- Open lines of communication allows for better coordination of services.
- Seeing an increase in community conversations regarding dementia and financial exploitation.
- Area agencies have respite funding and support groups.
- Employee assistance programs.
- National Task Group on Intellectual Disabilities and Dementia has an excellent screening tool.

III. Issues in Developmental Disabilities and Dementia

There are an increasing number of adults with developmental disabilities who are surviving to old age. As these individuals age, they are at greater risk of developing the signs and symptoms, like their peers in the general population, of Alzheimer's disease and related dementias. Population studies show that the rate of occurrence of Alzheimer's disease and related dementias among persons with developmental disabilities appears to be about the same as in the general population (or about 12% of persons age 60 and older). The rate among same-age adults with Down syndrome is much higher with some studies showing rates of Alzheimer's disease as high as 70% after the age of 65.

Dementia Risk Factors

Individuals with developmental disabilities may have a higher prevalence of Alzheimer's disease or a related dementia as a result of a number of risk factors:

- **Down syndrome** - A genetic disorder caused when abnormal cell division results in extra genetic material from chromosome 21. This genetic disorder, which varies in severity, causes lifelong intellectual disability and developmental delays, and in some people it causes health problems. Down syndrome is the most common genetic chromosomal disorder and cause of learning disabilities in children.
- **Significant head injuries** – (Chronic Traumatic Encephalopathy) Repeated head trauma triggers progressive degeneration of the brain tissue, including the build-up of an abnormal protein called tau.
- **Obesity** - higher prevalence of obesity than the general population.
- **Limited cognitive reserve** - Higher cognitive reserves, associated with high levels of cognitive capabilities, educational attainment and literacy, have been found to be protective and delay onset of dementia, while lower levels increase vulnerability. Due to the lifelong presence of substantial cognitive and functional limitations that define developmental disabilities, individuals may have increased vulnerability to development of dementia.
- **Poor cardiovascular health** - Some developmental disabilities are associated with congenital heart disease. The most common kind of heart disease in people with developmental disabilities is atherosclerotic heart disease, caused by narrowing of the arteries that take blood to the heart.

Down syndrome and Alzheimer's

People with Down syndrome have significantly higher rates of Alzheimer's disease than do other adults. There is a growing body of research that suggests that people with Down syndrome also experience premature aging, perhaps as many as 20 years earlier than other adults. This premature aging may help explain why many adults with Down syndrome are in their mid to late 40s or early 50s when symptoms of Alzheimer's disease first appear, compared to the late 60s for adults with other developmental disabilities.

Not all adults with Down syndrome will exhibit the symptoms of Alzheimer's disease, but upon autopsy nearly all show the associated brain changes (neuropathology). Men and women seem to be equally at risk. The progression of the disease is somewhat shorter for those in the general population, on the average, about eight years. The trajectory of the disease progression generally mirrors that of other people, but is compressed due to the shorter longevity of adults with Down syndrome.

The symptoms of Alzheimer's are sometimes expressed differently in adults with Down syndrome. In the early stages of Alzheimer's, memory loss is not always noted, and not all symptoms generally associated with Alzheimer's disease will occur. Changes in activities of daily living skills and personality are often the first signs noted. In some adults late-onset seizures may occur. Changes in cognitive function (thinking) may also be present, but they are often not readily apparent, or initially they may be ignored because of limitations in the individual's general level of function and a belief that the changes being observed are the result of the underlying disability.

**DIAGNOSTIC OVERSHADOWING:
THE PROCESS OF ATTRIBUTING
SYMPTOMS TO A DEVELOPMENTAL
DISABILITY LEAVING OTHER
CONDITIONS, SUCH AS DEMENTIA,
UNDIAGNOSED AND UNTREATED.**

Often referred to as *diagnostic overshadowing*, this failure to recognize that the behavioral and personality changes being observed may be due to a disease process such as dementia. As a result, appropriate supportive services may not be made available to them in a timely manner, resulting in diminished quality of life.

Marginalization in Policy and Practice

Individuals with developmental disabilities have made great strides in past years towards greater inclusion, empowerment, and self-advocacy. While there is a great deal of research literature about supporting individuals with developmental disabilities and, separately, about people with dementia, there is not the same knowledge about caring for and supporting individuals who have both developmental disabilities and dementia. The onset of dementia further marginalizes individuals. The lack of an evidence base contributes to the lack of knowledge in practice with formal and informal caregivers often unsure of available supportive services and programs.

Screening for Dementia

There is no single 100% reliable diagnostic test for Alzheimer's disease that can be used equally well with all adults. If dementia or Alzheimer's disease is suspected, a complete medical examination (including blood work, CT scan or an MRI) as well as neurological and psychological evaluations are strongly recommended.

Screening instruments used with the general population, such as the Mini Mental Status Examination, are generally not applicable because of the broad inconsistency of inherent cognitive abilities. Guidelines issued by the American Association on Intellectual and Developmental Disability, and the International

Association for the Scientific Study of Intellectual Disabilities (and available on these organizations' websites) offer suggested screening and evaluation procedures.

An excellent fact sheet on obtaining a differential diagnosis of dementia by Lauren R. Moo, M.D. Neurology Service, Cognitive Behavioral and Epilepsy Units Massachusetts General Hospital and Harvard Medical School, is available online at www.people.bu.edu/abudson/DDx-Dementia-Syllabus-2009.pdf.

The National Task Group on Intellectual Disabilities and Dementia Practices has also developed a screening tool. The *Early Detection Screen for Dementia* is an easy- to-use early detection and screening instrument that can be reliably used by both informal caregivers and paid staff. It is adapted from several sources, including the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (developed by Deb et al., 2007) and the Dementia Screening Tool (2010; Philadelphia Coordinated Health Care Group). It uses comorbidity items adapted from the Longitudinal Health and Intellectual Disabilities Survey developed by Rimmer and Hsieh (2012) at the University of Illinois at Chicago. The *Early Detection Screen for Dementia* can also be used to help identify those individuals with dementia-like symptoms whose function and behavior are the results of other causes (such as thyroid disorders, medication interactions, depression, etc.), offering family and professional caregivers a resource to record their observations regarding changes in areas of cognitive and adaptive functioning known to be associated with dementia. Family caregivers should know that this is not an instrument for the diagnosis of dementia. The intent is that caregivers will use the information captured to begin a dialogue with health care practitioners that will serve as an aid to shared decision-making.

As is true in the general population, a definitive diagnosis is only available after death. For a possible or probable diagnosis of Alzheimer's disease or other dementias, a well-documented progression of symptoms over time is necessary. Evaluations should be performed at select intervals using the person's previous performance as the comparison measure. The National Task Group recommends that screening for dementia begin at age 40 for adults with Down syndrome and at the onset of observable changes in behavior and personality in adults with other forms of developmental disability.

The Early Detection Screen for Dementia is available at no cost and can be downloaded online at www.aadmd.org/ntg/screening.

Generally, a general practitioner, specialist physician, neurologist, or geriatrician is a starting point for obtaining a diagnosis. Maine also has several specialized centers for the evaluation and treatment of people with memory disorders, dementia, or Alzheimer's disease known as Geriatric Evaluation Centers. These centers provide geriatric evaluations and assessment procedures, in addition to other services. A complete listing of these centers is available in the Maine Aging and Disability Resource Directory 2014. Copies of the Directory are available through regional Aging and Disability Resource Centers or online at www.maine.gov/dhhs/oads.

Challenges in Providing Services

Theoretically, adults with developmental disabilities and dementia should be able to receive appropriate services in any long term care facility. However, there are numerous reports in the literature that suggest that for a variety of reasons, people with developmental disabilities do not do well in facility-based long term care. Researchers have suggested that may be due to:

- Lack of disability-specific skills
- Lack of acceptance and integration of people with developmental disabilities, often because they are younger than other residents
- Social isolation due to age differences
- Perception that individuals with developmental disabilities are more difficult to care for

Developmental Services

Aging clients pose a significant challenge for developmental service providers that have not historically cared for elderly clients and lack the skills needed to provide that care. The elder care network is likewise inexperienced in providing care for individuals with developmental disabilities. Because policy is slow in evolving it is likely that the responsibility of care for adults with both developmental disabilities and dementia will fall to the disability service provider sector. Providers can expect to find it challenging to continue to deliver the services and programs they have historically offered while developing new services and programs specific to adults with dementia. New service needs will include, but not be limited to:

- Medication management
- Management of grief and loss for staff and clients
- End of life planning and palliative care
- Management of increasing cognitive impairment
- Transition planning for finances, retirement, changes in personal interests, and legal affairs.
- Health maintenance in the face of illness and functional decline.
- Increasing costs per client due to increased staffing needs
- Aging and death of family caregivers

Staff Training

There is no dementia specific training required for Direct Support Professionals and limited awareness of available resources.

Challenging Behaviors

People with dementia may sometimes behave in challenging ways, for example: aggression, paranoia, hitting, spitting, and shouting out. Behavior changes in dementia patients are almost universal. There are number of reasons why a person with dementia may act aggressively. Behavioral changes in dementia are often due to the individual lacking the ability to understand what is happening, and/ or have unmet needs they cannot communicate. They may be unable to regulate their own emotions due to damage to the part of the brain that controls emotional regulation, and may become abusive and aggressive. They may show disinhibition or do socially inappropriate/ unacceptable things. An unsuitable physical environment could also make things difficult for the person and result in behavioral outbursts. Unrealistic expectations of staff and other persons around them can also add to the problems the person is facing. Responses of staff (such as frustration/ anger/ facial expressions) can make the persons behavior more challenging. Finally, the inability to communicate pain in non-verbal adults is often the cause of angry and agitated behavior.

Behaviors of all kinds in a person with dementia, including those considered dangerous or maladaptive, are caused by a combination of factors, and cannot be viewed as an isolated problem to be solved independently. Unfortunately, even in the general population, adults with dementia are at risk for inappropriate use of antipsychotic medications, as well as abuse. To ensure that the intent of the behavioral regulations in Maine statute extends to adults with dementia it will be imperative that direct care staff, administrators and supervisors, case managers, and clinicians receive training in the causes of and non-pharmacologic treatment of challenging behaviors in adults with developmental disabilities and dementia to minimize the chance of the behaviors that are so common in dementia being misunderstood as dangerous or maladaptive.

Behavioral Regulations and Safety Devices

For persons receiving Developmental Services, Maine statute governs the use of emergency interventions and behavioral treatment in a manner consistent with safety, well-being, independence, and inclusion. The regulations acknowledge that these goals may need to be achieved by means of “systemic behavioral treatment.”

Two definitions have potential impact on adults with developmental disabilities and dementia:

- Dangerous behavior - behavior that imperils safety or is likely to cause injury or pain to self or others.
- Maladaptive behavior – behavior that is an inadequate, dangerous, harmful or socially unacceptable response to circumstances or events, or interferes with the individual’s acquisition or performance of appropriate and prosocial behaviors.

Although the regulations include many safeguards for the use of inappropriate behavioral treatments, including the requirement that alternative techniques must have “tried and failed” and that “a behavioral assessment and documented efforts to address the dangerous or maladaptive behavior by the use of less intrusive or more positive techniques have been systematically tried and determined to be ineffective,” the potential for inappropriate behavioral interventions for individuals with dementia remain.

Experienced dementia practitioners understand that the use of these some psychotropic medications carry significant medical risks in older adults and that non-pharmacologic interventions are often more effective in managing and accommodating challenging behaviors. By limiting review of medications to those that “immobilize” a person, Maine is missing an excellent opportunity to reduce the inappropriate use of medications in this population.

Examples of commonly accepted devices used in caring for individuals with dementia would be door alarms, door knob covers, half doors to prevent a person with dementia from wandering into another person’s room uninvited, and chair alarms to alert staff if a person with dementia (who represents a fall risk) tries to rise from a chair, etc.

Safety devices used in commonly accepted practice for individuals with dementia could potentially result in useful safety devices not being utilized due to a burdensome approval process. This is an area where cross-sector collaboration between the aging and developmental disability networks might inform policy and regulations in areas where accepted dementia practices might conflict with regulations and statutes.



IV. Services & Programs for Adults with Developmental Disabilities and Dementia in Maine

Underlying principles of care for people with developmental disabilities and dementia

The Edinburgh Principles were developed and issued through the International Association for the Scientific Study of Intellectual Disabilities and support:

- A general belief of continued community care and a focus on the individual,
- Use of specially designed dementia capable environments and services, and
- Careful planning that includes adults with developmental disabilities in generic dementia-related services and resource allocations.

In essence, the Principles state that services should:

- Promote a person-centered approach,
- Focus on individual strengths, capabilities, skills and wishes,
- Involve the individual, her/his family and other closest supports in all phases of assessment and services planning and provision, and
- Provide supports/services that help the person remain in his or her chosen home and community.

The Principles can be viewed and downloaded at www.iassid.org.

Services needed by adults with developmental disabilities and dementia

Research has shown that people with developmental disabilities and dementia can continue to live in the community assuming the right supports and assistance are provided. Because persons will, at some point, not be able to continue to live on their own, "dementia capable" housing and supports need to be provided. Additionally, use of adult care programs can provide an atmosphere where varied and challenging activities, as well as supervision, are available. If sufficient supportive services can be put in place it is possible to delay, if not prevent, admission to a nursing facility or other institutional setting. The same types of day-to-day accommodations for adults in the general population are needed by persons with developmental disabilities.

There are a variety of programs designed to serve individuals with developmental disabilities in Maine, although none specifically address dementia-capable services. Maine's aging network programs have been relatively successful in meeting the specialized needs of people with dementia and their families through innovative programming; however aging adults with developmental disabilities are generally not served in these programs.

With the projected increase in adults over the age of 65 it is unlikely that Maine will have the service infrastructure necessary to support the growing demand of individuals with dementia and their families. Complicating the demand for services is the fact that planning for the aging population with dementia has historically focused on the general population with little or no recognition of the unique challenges faced by individuals with lifelong co-occurring disabilities.

Although there are multiple portals to access services for individuals with dementia they are not well known to the service providers or the families of individuals with developmental disabilities. In addition, many publicly funded programs are limited to individuals over the age of 65 – a clear limitation to access by individuals with Down syndrome who generally develop Alzheimer’s disease in their 50’s.

Health Care

People with disabilities have higher rates of disease and chronic health conditions than people without disabilities and confront numerous barriers to maximizing their health and function.

Stakeholders consulted for this report consistently indicated that Maine’s current health care system is substantially deficient with respect to meeting the needs of adults with developmental disabilities generally, and those experiencing the onset of dementia specifically. It appears that there is a shortage of physicians who are willing to see MaineCare patients in part because of the low reimbursement rates for services and lack of risk-based fee adjustments.

As a result, illness is often unrecognized, misdiagnosed or undertreated. Anecdotal evidence suggests that the onset of dementia is often mistaken as a byproduct of their underlying disability (“diagnostic overshadowing”) with the behavioral changes they experience explained away as “oppositional behavior” as opposed to early symptoms of dementia.

Barriers to health care for adults with Developmental Disabilities were reported to be:

- **Communication challenges due** to cognitive and verbal limitations. Individuals are commonly unable to identify pain, describe symptoms of illness, or explain signs of discomfort to physicians. For non- verbal persons, pain may manifest itself as a behavioral issue and go unrecognized, misdiagnosed or undertreated.
- **Complex medical needs are greater** relative to the general population, resulting in longer patient visits and the need for more interdisciplinary care management. Primary care physicians and specialists do not receive reimbursement to coordinate care.
- **Lack of knowledgeable providers:** Informants overwhelmingly agreed that adult health care providers, including dentists, lack training, experience and comfort in caring for people with a developmental disabilities. One theory explaining this is that the typical medical school curriculum does not provide training except for those specializing in pediatrics. Anecdotal evidence also suggests that many primary care physicians are not skilled in diagnosing dementia in the general population. When an adult with developmental disability develops symptoms suggestive of the

onset of dementia the problem of finding physicians skilled in providing a proper differential diagnosis becomes even more difficult.

- **Lack of physicians:** The amount of time needed to conduct patient visits and financial disincentives contribute to a shortage of physicians who will accept patients with developmental disabilities.
- **Low reimbursement rates:** MaineCare and Medicare reimbursement rates do not account for the extended period of time needed to properly assess and treat a person with complex conditions. One geriatrician noted that seeing patients with complex needs causes him to operate at a net loss because current reimbursement rates do not account for the amount of time and skill needed to thoroughly assess the complex needs of aging adults.

Although many physicians deal with aging, geriatric medicine is widely considered to hold the greatest depth of expertise in dealing with the complex medical and psychosocial problems of older adults, especially those with dementia. Geriatricians have special knowledge and training in the aging process and special skills in the diagnostic, therapeutic, preventive, and rehabilitative aspects of illness in the elderly. Evidence suggests, however, that few geriatricians in Maine treat adults with developmental disabilities.

Determining which physicians in Maine hold board certification in geriatrics yields mixed results at best. The American Board of Family Medicine lists 27 physicians in Maine holding specialty certification in geriatrics. A search for geriatric physicians in Maine on Healthgrades.com, an online comprehensive physician rating and comparison database, returned 91 physicians claiming to be board certified geriatricians. A search of the Maine Board of Licensure in Medicine for physicians and physician assistants using the keyword “geriatric medicine” returned no results.

An online search for Maine physicians specializing in developmental/intellectual disabilities returned no results. Underscoring this inability to easily identify physicians with expertise in this area is this quote from the 2013 Health Care Safety Net Series “Leveraging Points in Delivery System Reform: Improving Care for Complex Patients” published by the Maine Primary Care Association.

“With people enjoying longer lives, the effects of aging can manifest in challenging ways for someone with an Intellectual/Cognitive Disability; for example, with memory loss and dementia. Because of the lack of training available, some medical providers may make assumptions about the developmental stage or comfort level of the patients which undermine the quality of care they provide.”

Lacking appropriate recognition of the onset of dementia, these individuals are at risk of the inappropriate use of antipsychotic medications to control behaviors with a compromised quality of life resulting.

Publicly Funded Services

MaineCare (Medicaid) is a program created by the federal government and administered by states to provide payment for medical services for low-income citizens. People qualify for Medicaid by meeting federal income and asset standards and by fitting into a specified eligibility category. MaineCare recipients must be U.S. citizens or legal permanent residents, and may include low-income adults, their children and people with certain disabilities.

Many Mainers with developmental disabilities rely upon Medicaid (known as MaineCare) for services and supports as well as for access to healthcare. Access to services and supports may require specific eligibility and wait lists exist for some services. There are several community based MaineCare programs and waivers that may serve persons with developmental disabilities and dementia. Eligibility and availability vary and are subject to change. MaineCare members may only receive services under one waiver benefit at a time. Persons who meet the criteria for Developmental Services may receive:

- **Section 21: Home and Community Benefits for Members with Intellectual Disabilities or Autistic Disorder:** Serves individuals with intellectual and/or developmental disabilities of all ages who meet the level of care provided in an intermediate care facility for individuals with intellectual disabilities and related conditions. The Section 21 Waiver is the most comprehensive waiver designed to support people in living within the community, and it offers a mix of services including: home support, community support, and work support. Other services are available and may be recommended for individuals through the person-centered planning process. To receive services, members must meet medical eligibility requirements and there must be a funded opening.
- **Section 29: Support Services for Adults with Intellectual Disabilities or Autistic Disorder:** Offers support services to individuals who live with their families or on their own. The primary services are community support and work support.

Over 4,000 Mainers receive MaineCare Section 21 or 29 services.

Others may receive services such as:

- **Section 19: Home and Community Benefits for the Elderly and for Adults with Disabilities** provide services which allow persons who need nursing facility level of care to remain at home while receiving the care that allows them to live independently in the community.
- **Section 20: Home and Community-Based Services for Adults with Other Related Conditions**
- **Section 50: Intermediate Care Facility –Intellectual Disability Services** are provided in institutional settings designed to meet the intensive active treatment needs of consumers.
- **Section 96: Private Duty Nursing and Personal Care Services**
- **Section 97: Private Non-Medical Institution Services**

V. Trends and Emerging Practices in Caring for Adults with Developmental Disabilities and Dementia

Aging in Place

At its simplest, “aging in place” means being able to grow older without having to move to obtain the supportive services needed as one ages. Generally speaking, aging translates into increasing needs that change over time. Older adults with developmental disabilities may be more susceptible to isolation as their natural support networks may not include children or a spouse. Continuing to live in a familiar environment is what we all desire as we age. Historically, as we age and our needs for support increase, a transition into a long term care facility has been the norm. Moving from the security and familiarity of home into an institutional setting is difficult at best for anyone. The transition is even harder for individuals with developmental disabilities.

Greater understanding of the impact of "relocation trauma," as well as the perceived financial savings of providing long-term care in non-institutional settings, coupled with the legal implications of the Supreme Court Decision in *Olmstead vs. L.C.* in 1999, has prompted policy makers and service providers to focus increasing emphasis on environmental designs and supportive services to support the ability of older people to continue living where they are. With its genesis in the general aging population, the concept of “aging in place” has been extended in recent years to other groups of individuals, including those with developmental disabilities who develop dementia.

THE CARE SETTING ONLY REMAINS APPROPRIATE IF THE SUPPORT PROVIDED MEETS THE SOCIAL, EMOTIONAL AND PHYSICAL NEEDS OF THE PERSON WITH DEMENTIA.

The majority of individuals with developmental disabilities live with family members. This frequently means that aging parents are caring for adult children who develop the same age-related impairments and illnesses as people who do not have life-long disabilities. Older adults with Down syndrome are unique among adults as they age prematurely, leading to earlier development of age-related infirmities and predisposing them to early onset Alzheimer’s disease.

Aging in place becomes significantly more difficult when dementia arises. Challenges reported in the literature include the person with dementia being seen as having “special privileges,” resentment by other clients if program or environmental adaptations are made, and difficulty (on the part of clients without dementia) understanding dementia related changes.

However, with proper support, older adults with dementia can remain in their homes. Their need for increased supports will grow regardless of where they reside. Studies indicate that aging-in-place can occur if providers receive appropriate training, are assisted in making the necessary environmental modifications to the residences, and provided with responsive and flexible funding.

Research has suggested that the following are critical elements for successful aging-in-place:

- Direct care professionals trained in dementia-capable care
- Staff resources including comprehensive assessment/screening and supervisor willingness to adjust staff patterns to reflect increasing needs of clients with dementia
- Support for informal family and friend caregivers including support groups and workshops.
- 24 hour staff supervision
- Health care professionals knowledgeable in aging, developmental disabilities, and dementia
- Environmental interventions to address changing sensory needs and safety
- Programmatic adaptations to accommodate dementia related impairments
- Assistive technology
- Assessment and screening for early onset of dementia
- Outreach and advocacy to raise awareness of issues
- Collaboration between aging and developmental disability service networks

Living options for aging adults with developmental disabilities are generally different from that of the general aging population. Adapting the environment to meet the needs of the person, rather than moving the person to a new environment has been found to minimize inappropriate levels of treatment and contributes to keeping the person in the least restrictive setting possible. Meeting the changing support needs of aging clients within the group home setting has been successfully addressed by adapting program services, adapting the environment, and using assistive technologies were appropriate.

FOR AGING IN PLACE TO BE A VIABLE OPTION SUPPORT LEVELS WILL NEED TO INCREASE AS THE DISEASE PROGRESSES.

Specialized Dementia-Capable Group Homes.

The caregiving challenges inherent in caring for an individual with developmental disabilities and dementia have given rise to the development of specialized dementia-capable small group homes, or “in-place progression” (Janicki and Dalton, 1999), especially for individuals in end-stage dementia.

Agencies that operate a number of group homes are, in some cases, opting to create specialized care units within one or more homes and transfer clients to these units as needed and appropriate. Each model has cost implications, staffing implications, and continuity of care implications. To ease transition, homes can be designed with similar layouts and features so that the physical environment feels familiar to clients who are transferred. Two popular models that are now being explored nationally involve using small group homes, each with three to five beds, to incorporate the supports that are needed in the various stages of dementia.

In the first model, one group home simultaneously serves individuals who are in various stages of dementia.

The second model uses multiple group homes, each geared toward serving individuals in a specific stage of the disease. As the dementia progresses, people move from one group home to the next. This model has some drawbacks since it involves moving people regularly and displacing them from a living site they know to be home. However, one study found some positive outcomes. Within a cluster of five group homes, three of which were geared toward each of the stages and two that housed people in all stages, the people residing in the houses with specialized activities for early dementia, stayed in the early stages for longer periods of time than those who lived among people in various stages.

A number of states either have developed or are planning to develop dementia specific group/congregate homes. More research is needed regarding the efficacy, cost effectiveness and appropriateness in Maine, given its large geography and small population.

Aging and Developmental Disability Services Cross-Sector Collaboration

Quoting a 2005 study, Stainton et al point out that “The aging and disability service systems have historically developed in parallel but separate tracks ... despite often overlapping concerns about issues such as affordable housing, public transportation, access to healthcare, long-term care needs, and economic stability.” As a result, the aging network lacks the disabilities-specific skills and experience needed to care for older adults with developmental disabilities and the developmental disabilities network lacks the aging-specific skills and experience needed to care for their aging population, particularly aging adults at risk of developing dementia.

Although this presents a problem, it also offers an opportunity to develop collaborative relationships. Aging network providers indicate that they do feel well equipped to provide care to individuals with developmental disabilities and developmental disabilities staff report they do not have sufficient experience in caring for persons with dementia. Current experience in Maine, as is true in most states, seems to point to a phenomenon of developmental disabilities service providers developing their own response to dementia. While this may be the answer to immediate needs it may not be practical to duplicate senior services. Coordination between systems would maximize resources and increase capacity to provide the most appropriate and cost-effective care.

One model of cross-sector collaboration to consider is happening in Canada. The Ontario Partnership on Aging and Developmental Disabilities was formed in 2000 as a result of a conference on aging. The premise of this partnership is that the best quality of support lies in the collaboration between aging and developmental disabilities systems of care.

The Ontario Partnership on Aging and Developmental Disabilities developed eight regional cross-sector committees that planned conferences to bring the two sectors together to discuss ways to develop partnerships. Ongoing work has created a system of connecting interested parties through technology and webinars. One successful initiative paired a long term care facility and a developmental disabilities service agency. Staff members toured each other’s facilities. An individual with Down syndrome was admitted to the long term care facility. The developmental disabilities agency provided intensive staffing support for the first few days following admission with ongoing staff support and education thereafter.

Developmental disabilities agency staff continued to provide support for four hours a week and was involved in all areas of planning including assistance with family support. Eight adults with developmental disabilities now live at the long term care facility with staff from the outside agency continuing to provide support. Partnerships have involved not only admissions into long term care facilities but also involve moving individuals from long term care back into the community.

Other successful state models have involved strategies such as collaborative retreats and reciprocal staff internships to improve understanding of how other agencies work and strengthen relationships.

Support for Family Caregivers

The need to support this “informal” system of care has frequently been unanticipated by federal and state policy. A number of studies have been done showing the physical, emotional, and financial impact of caregiving on families. Because Maine has such a large percentage of aging citizens it can be anticipated that the need for supporting this informal network of care will increase exponentially. Many states are working on improving coordination between Older Americans Act services (provided through regional Area Agencies on Aging) and services. States are also working to reduce waiting lists for home and community-based services.

Professional Development

Understanding the changes in caregiving needs related to aging and the onset of dementia are critical aspects of providing appropriate care to aging adults with developmental disabilities and dementia. Caring for aging adults with developmental disabilities and dementia requires a shift in care philosophy from “rehabilitation” to “habilitation” or from promoting independence (“active treatment”) to maintaining functioning and comfort care. Numerous studies have shown evidence of the beneficial impact of staff training on meeting the support needs of adults with dementia in the general population in the areas of decreased caregiver burden and stress and decreased use of antipsychotic medications to manage challenging behaviors. It could be anticipated that similar results would be found among persons with developmental disabilities.

Specialization

Some agencies in other states are allowing staff to specialize in dementia care as a means of increasing staff effectiveness and satisfaction.

Curriculum

The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) has developed a new national model staff training curriculum that will be available to states in early 2015. Information on the new training curriculum is available from NTG curriculum co-chairs Dr. Kathleen Bishop (bisbur@earthlink.net) or Kathryn Pears, MPPM (dementiacare@gwi.net).

Technology

A variety of assistive devices and technologies have been developed to support individuals with dementia generally and could be of benefit to adults with developmental disabilities.

An excellent resource for dementia-specific assistive devices is The Alzheimer's Store (www.alzstore.com).

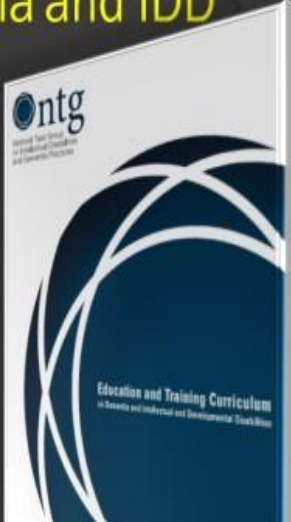
Maine also has an asset in Dr. Chip Teel in Damariscotta. Dr. Teel is an expert in the use of technology to support aging individuals as well as those with dementia to age-in-place. www.fullcircleamerica.com

NTG Education & Training Curriculum on Dementia and IDD

New national curriculum currently in development

Curriculum will have several levels

- **Level 3:** Core curriculum for staff employed in programs directly serving adults with ID and dementia
 - extensive content on in-depth knowledge of dementia and dementia capable care
- **Level 2:** Content for staff employed and participating in a continuing education program
 - content on basic knowledge of aging and dementia
- **Level 1:** Content for new hires participating in



VI. Developmental Disabilities and Aging Service Networks

The Developmental Disabilities Assistance and Bill of Rights Act establishes statewide systems of community systems and supports whose mission is to support community-based delivery of services to persons with developmental disabilities, and to create and enhance opportunities for independence, productivity, and self-determination. Three programs comprise what is sometimes referred to as the “DD Network”. Although they have different mandates, these programs work in a collaborative and complementary fashion.

- **State Councils on Developmental Disabilities** (Maine Developmental Disabilities Council) - Councils are charged by Federal law to identify the most pressing needs of people with developmental disabilities in their State or Territory and to develop innovative and cost effective ways to address those needs in a manner that upholds the dignity and value of people with developmental disabilities.
- **University Centers for Excellence in Developmental Disabilities Education, Research, and Service** (University of Maine Center for Community Inclusion and Disability Studies) – Public service units of universities serve as liaisons to service delivery systems to positively affect the lives of individuals with developmental disabilities and their families.
- **Protection & Advocacy Systems** (Disability Rights Maine) – Provide legal representation and other advocacy services to all people with disabilities, investigate charges of abuse and neglect, and provide information and referral.

Office of Aging and Disability Services, Maine Department of Health and Human Services: Responsible for planning, developing, managing, and providing services to promote independence for elders and adults with brain injuries and intellectual and physical disabilities through the provision of services. These include evidence-based prevention programs and comprehensive home and community-based services including Adult Protective Services and Public Guardianship and Conservatorship Programs. Disabilities Services supports individuals with intellectual disabilities, autism, brain injury and physical disabilities.

Community Service Providers: Maine community service providers offer a range of supports and services to children and adults with developmental and other cognitive disabilities.

Area Agencies on Aging: Were established by the Older Americans’ Act of 1965 to provide services to older persons (60+) not adequately served by other public and private systems and to provide advocacy at the federal, state and local levels to encourage other systems to be more responsive to the needs of the elderly. Area Agencies on Aging are public or nonprofit private agencies designated by the State to carry out the Older Americans Act at the regional level. Funds are distributed to states, territories, the District of Columbia, Indian tribes and native Hawaiians on a formula basis which provides minimum funding levels to small population groups and sparsely populated states and proportional funding levels based on state elderly populations of the majority of the other states. Funds are provided in the form of grants for

various programs authorized under the act and states have some limited latitude in administering these monies in local areas.

There are 5 local Area Agencies on Aging in Maine located regionally:

- Southern Maine – York and Cumberland counties
- Senior’s Plus – Oxford, Androscoggin, Franklin counties
- Spectrum Generations – Kennebec, Lincoln, Waldo, Somerset, Knox, Sagadahoc
- Eastern Area – Penobscot, Piscataquis, Washington, and Hancock counties
- Aroostook Area – Aroostook county

The Area Agencies on Aging in Maine are the administrators of the following programs:

- **Aging and Disability Resource Centers:** Provide information and assistance to individuals seeking information on local resources, professionals seeking assistance for their clients and individuals planning for their future long-term needs. People of all ages, incomes and disabilities can obtain information on the full range of long-term support options available in their communities.
- **National Family Caregiver Program:** Older caregivers providing care to their adult children with disabilities can be served in this program if the adult children are 60 years of age and older. Services offered include:
 - information to caregivers about available services,
 - assistance to caregivers in gaining access to the services,
 - individual counseling, organization of support groups, and caregiver training,
 - respite care, and
 - supplemental services, on a limited basis.

Legal Services for the Elderly: Provides persons age 60 and over with free legal advice regarding health care, health insurance, Medicare (including Part D), MaineCare (Medicaid), Social Security and other public benefits, pension and retirement benefits, powers of attorney, consumer matters including creditor and bankruptcy problems, physical and financial abuse, guardianship defense and other issues. Clients call the toll-free number, 1-800-750-5353, and talk with a Helpline attorney about their problems. If the Helpline attorney is unable to resolve a client's problem, the client then is referred to a staff attorney at the office which is situated closest to the client's town for extended representation.

Long Term Care Ombudsman Program: A non-profit agency whose mission is to advocate for quality of life and care for long term care consumers. Federal law and Maine law authorize their staff to investigate complaints made by or on behalf of long-term care consumers and to assist them in exercising their rights that are guaranteed by law. This program serves residents of nursing facilities and assisted housing programs, including residential care facilities and assisted living facilities. In addition, they serve recipients of home care services, adult day services and homemaker services. The Maine Long-Term Care Ombudsman Program helps with information, guidance and advocacy. Their services are free and confidential. For more information or assistance, contact them at 1-800-499- 0229 or (207) 621-1079.

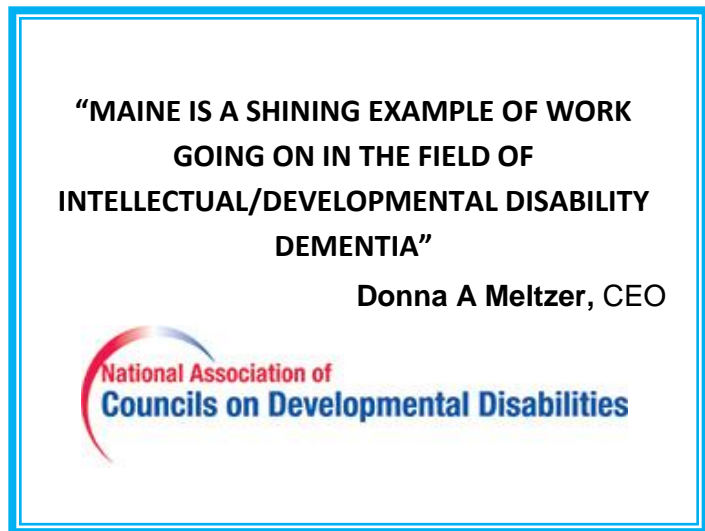
VII. Promising Practices

State Initiatives

Maine is considered to be in the forefront of developing services and programs that are dementia-capable. A number of initiatives are underway that represent excellent opportunities for not only increasing awareness of the unique needs of a person with a developmental disability but are also areas of current Maine program and service delivery restructuring where active advocacy of inclusion of the needs of this population should be taking place.

Balancing Incentives Program

The Maine Balancing Incentive Program holds the promise of providing new ways of addressing the increasing demand for services in home and community-based settings. This initiative is in keeping with the integration mandate of the Americans with Disabilities Act, as required by the Olmstead decision.



Maine plans to leverage the Balancing Incentive Payment Program to further develop Maine’s systems of community-based long term services and supports. As part of this initiative, Maine commits to increasing the share of expenditures for community services so that it equals or exceeds the expenditures for institutional services. Areas of the Balancing Incentives Program that could hold specific promise for individuals with developmental disabilities and dementia are:

- **Improve access to Long Term Support Services for all populations.** To improve quality of care, integrate physical health care, treatment for addictions, mental health treatments, and services to individuals with intellectual disabilities that have historically been provided in silos. Maine plans to alleviate existing fragmentation and improve access while still recognizing and identifying program differences that should be preserved to meet each population’s distinct needs.
- **Increase Aging and Disability Resource Center’s visibility and capacity.** To assist younger individuals with all disabilities, Maine proposes to develop comprehensive statewide visibility and consistency in this area as well as expand target outreach.
- **Expand independent assessing services for Long Term Support Services eligibility to include adults with developmental disabilities.** The goal is to create efficiencies and provide streamlined eligibility and referral services.
- **Unify the application process for all populations using Long Term Support Services and provide comprehensive and consistent information statewide.** Remove barriers to accessing

services for individuals accessing system for the first time by unifying the application process for all populations and providing comprehensive and consistent information statewide. A standardized screening is envisioned, as well as other on-line web based tools to complete eligibility screening.

- **Enhance outreach to underserved and unserved populations.** Maine will focus on providing comprehensive outreach across all populations, including culturally diverse, underserved and unserved populations. For more information on the Maine Balancing Incentive Program: www.balancingincentiveprogram.org/state-activities/maine

“Supporting Individual Success” Initiative

Combines use of a standardized assessment tool called the Supports Intensity Scale with a resource allocation model for individuals with developmental disabilities. Policy goals identified for this project are:

- Fairness, equality, explicability
- Increase efficiency to meet increasing demand
- Match resources and individual needs
- Ability to handle exceptional care
- Focus on those with greatest need in a time of limited resources
- Inject self-directed approaches

The assessment tool, currently used in 29 states, was developed by the American Association on Intellectual and Developmental Disabilities and has been chosen by the Department as a requirement for adults receiving Developmental Services. It measures practical support that an individual needs to be successful in the community. The intent is to achieve a more equitable and sustainable model for service delivery, including waiver services. Goals for use of the tool include increasing person-centeredness, self-direction, employment and community inclusion. Inherent in the initiative is a focus on specialized supports, including those to address complex or unique needs. Because individuals with developmental disabilities who develop dementia “require specialized supports to address their complex and unique needs” it would be prudent to ensure that the dementia-specific needs of this population be considered in the planning and implementation of this resource allocation tool.

For Adults with Developmental Disabilities and Dementia: Because the tool captures both medical AND behavioral needs, it could potentially result in more accurate representation of the resource needs of individuals with dementia.

Maine Direct Service Worker Online Training Program

Maine was one of six states awarded Health Resources and Service Administration funding to develop, implement and evaluate a competency-based curriculum and certification program to train qualified personal and home care aides. Ten core competencies were identified, one of which was training specific to an individual consumer’s needs including older individuals, younger individuals with disabilities, individuals with developmental disabilities, individuals with dementia, and individuals with mental and

behavioral health needs. A certification test is also required. Maine was unique among grantees as it will deliver the curriculum on-line via distance education to expand access to training in rural areas of the state.

For Adults with Developmental Disabilities and Dementia: A specialized module for Direct Support Professionals addressing dementia that is offered online could benefit workforce training needs, especially in rural areas of the state. For more information on the Maine Direct Service Worker Training Program: <http://www.maine.gov/dhhs/mainedirectserviceworker/>

Southern Maine Area Agency on Aging/Dementia Capable Service Network Grant

The Southern Maine Area Agency on Aging/Aging and Disability Resource Center was awarded a \$1 million grant from the federal government to develop additional services for targeted special populations and evidence-based training for caregivers and service providers of those with Alzheimer's disease and related dementias and for people with intellectual and developmental disabilities aging into dementia. In part, the project will develop partnerships and expand methods to identify and deliver quality, effective services to persons with developmental disabilities and caregivers. As part of the grant, funding was requested to offer the National Task Group on Intellectual Disabilities and Dementia's new national model curriculum. Information on the NTG curriculum is available on their website: <http://aadmd.org/ntg>.

For Adults with Developmental Disabilities and Dementia: Specific targeting is a significant step forward in raising awareness and increasing the dementia-specific knowledge of Maine's professional caregivers in Maine's community-based developmental service programs.

Savvy Caregiver Program

The Savvy Caregiver Program is an evidence-based psychoeducational program developed by Dr. Kenneth Hepburn at Emory University in Georgia. The program is a six week, two-hour per week intervention designed for family caregivers of individuals living at home or in the community. The Savvy Caregiver Program was initially implemented in Maine as part of an Administration for Community Living grant that ran from 2008 thru the end of February 2014 and was administered by the Maine Department of Health and Human Services, Office of Aging and Disability Services. Near the end of the project the target audience was expanded to include a pilot training for individuals caring for adults with developmental disabilities and dementia. One pilot training was held in Bangor prior to the end of the grant and was attended by several Direct Support Professionals. The grant has ended but the Savvy Caregiver Program has been embedded into the Family Caregiver Program at each of the state's five Area Agencies on Aging. For additional information on the Savvy Caregiver Program and how it might be made available, contact Christine Merchant at Christine.Merchant@maine.gov.

For Adults with Developmental Disabilities and Dementia: All five Area Agencies on Aging have staff trained as Savvy Caregiver Master Trainers. If sufficient interested family caregivers could be identified regionally it is likely that a regional Area Agency would be willing to collaborate with a local community service provider to offer the training to their families.

Charlotte White Center Specialized Dementia Housing Project

For Adults with Developmental Disabilities and Dementia: The Charlotte White Center project represents the first attempt in Maine at developing a dementia-specific housing option. The Center is in the early stages of developing this program.

Federal Initiatives

National Alzheimer's Project Initiative

The National Alzheimer's Project Act creates an important opportunity to build upon and leverage federal Health and Human Services programs and other federal efforts to help change the trajectory of Alzheimer's disease and related disorders. The law calls for a National Plan for Alzheimer's disease and related disorders with input from a public-private Advisory Council on Alzheimer's Research, Care and Services. The Advisory Council will make recommendations to Department of Health and Human Services for priority actions to expand, coordinate, and condense programs in order to improve the health outcomes of people with Alzheimer's disease and related disorders, and reduce the financial burden of these conditions on those with the diseases, their families, and society. The interests of individuals with developmental disabilities and dementia have been actively represented by the National Task Group on Intellectual Disabilities and Dementia Practices co-chairs, Dr. Matt Janicki and Dr. Seth Keller.

Geriatric Education Centers

Geriatric Education Centers provide interdisciplinary geriatric education and training to health professionals and other students. As a direct result of National Task Group advocacy on the initiative, Geriatric Education Center's will be receiving supplemental funding from the federal government to provide inter-professional training on developmental disabilities and dementia.

Screening and Detection of Dementia

A dementia screening tool has been developed specific to adults with developmental disabilities. The National Task Group Early Detection Screen for Dementia is an informant-based rating tool for use with adults with intellectual and developmental disability who are suspected of having changes in thinking, behavior, and adaptive skills suggestive of mild cognitive impairment or dementia. It is considered an administrative, and not a clinical assessment tool. It was not designed to diagnose dementia, but to help in the early identification and screening process, as well as to provide information to begin the dialogue with health care professionals. Persons who complete this instrument are asked to indicate whether they have observed the occurrence of new problems or a worsening of problems that have previously been observed. The items are associated with changes in cognition, behavior, mood, and activities of daily living. It has been translated into seven languages and is available online at no cost at: <http://aadmd.org/ntg/screening>.

VIII. Recommendations

1. Increase awareness of dementia and developmental disabilities among:

- **Persons with Disabilities and Families:** Increased understanding of risks will allow individuals and families to more effectively plan for their futures, access the most appropriate services and more effectively advocate for themselves.
- **State agency personnel:** Although Maine is one of a handful of states that are at the forefront in developing systems to meet the unique and often challenging needs of aging adults with developmental disabilities who develop dementia, much remains to be done. Raising the visibility of the issues is the first step and needs to take place within both the developmental disabilities and the aging networks of services.
- **Elected representatives:** Maine has a rich history of addressing the needs of aging adults with dementia in the general population. However, there is little awareness among policymakers of the unique needs of aging adults with developmental disabilities generally or those with dementia specifically. Ensuring adequate and fair allocation of scarce state and federal funds is imperative to meeting the support needs of these individuals.
- **Developmental Disability Providers:** Currently, there are individual providers who are delivering effective person centered supports for individuals with dementia, as well as providers who are not dementia-capable at all. Lack of coordinated regional or statewide planning and collaboration limits access to quality evidence based services and may increase costs.
- **Health and Long Term Care Professionals:** Inadequate awareness of the impact of dementia among health care providers can result in significant challenges to persons with developmental disabilities accessing appropriate health care.

2. Increase Integration of Services and Supports:

Historically, aging and developmental disability services have existed in effective silos. While there have been recent efforts at the state and federal level to increase integration of disability related services and supports across the lifespan, effective collaboration is still too often dependent upon the commitment of individuals rather than planned integration of knowledge, services and support. Individuals and families impacted by developmental disability and dementia should receive quality, consistent, coordinated support however they access the system. Integration of services and supports will require the involvement of:

- **State Agencies:** primarily the Office of Aging and Disability Services, but also including other agencies where families access systemic care, such as MaineCare Services and income-based supports;
- **The Aging Network:** including the Aging and Disability Resource Centers, the Area Agencies on Aging and service providers;

- **Developmental Disability and Aging service providers; Health Care Providers; Other Advocacy Organizations:** such as Maine Council on Aging, American Association of Retired Persons, the Alzheimer’s Association, etc.; and
- **Research and Education Entities:** such as the Maine Center on Aging.

3. Expand Systemic Capacity

Workforce Development: Increase the availability of elder services providers able to address developmental disability and dementia capable developmental services providers

- **Southern Maine Agency on Aging Dementia Grant:** The Southern Maine Area Agency on Aging has received a large federal grant to develop services for adults with dementia and has specifically included adults with developmental disabilities in the proposal. One of the activities they are undertaking is sponsoring the National Task Group’s Direct Support Staff Curriculum Workshop in 2015.
- **DSP Online Training Module on Developmental Disabilities and Dementia:** The Muskie School of Public Service has developed the Maine Personal and Home Care Assistance Training Program targeting personal and home care assistance workers, including Direct Support Professionals.

Enhance Family Support Services: including education, referral and diagnosis, clinical supports, and respite.

Specialized Group Homes for Dementia Care. As dementia progresses, specialized care (including hospice and nursing supports) is needed. As awareness of the unique needs of adults with developmental disabilities and dementia become more prevalent it can be anticipated that agencies will recognize specialized dementia care as a necessity and devote resources to the development of one or more small purpose group homes designed specifically for dementia.

4. Adopt Evidence Based Screening Practices: The National Task Group has developed an easy to administer screening instrument called the Early Detection Screen for Dementia for early detection screening of those adults with a developmental disability who are suspected of, or may be, showing early signs of mild cognitive impairment or dementia. It is recommended that this instrument be used on an annual or as indicated basis with adults with Down syndrome beginning with age 40, and with other at-risk persons with intellectual or developmental disabilities when suspected of experiencing cognitive change. It was designed to be used to detect ‘cognitive impairment’ among adults with intellectual disabilities as preparation for the annual wellness visit requirement under the Patient Protection and Affordable Care Act. It can also be used to identify those individuals with dementia-like symptoms whose function and behavior are the results of other causes (such as thyroid disorders, medication interactions, depression, etc.).

5. Improve Data

Impact of dementia among family caregivers:

To preclude institutional placements and to support families with continued caregiving state level research needs to be conducted on the impact of dementia upon family caregiving. The onset of dementia in their adult children will tax the ability of these families to continue to provide care.

Impact of dementia among people with developmental disabilities receiving services and supports.

Little is known about how many persons with dementia are currently receiving Developmental Services, nor are accurate estimates available about how many will need services in the future. Accurate data on the number of adults currently in the system with dementia as well as projections on future numbers is vital to assuring adequate and fair distribution of scarce state financial resources. Improved data will also allow for better regional or statewide coordination of supports for low incidence needs.

IX. References

- Alzheimer's and dementia in the oldest-old: a century of challenges. *Current Alzheimer's Research*. 2006 Dec; 3(5):411-9. Kawas CH, Corrada MM.
- Monetary Costs of Dementia in the United States. *The New England Journal of Medicine*, v. 368, no. 14, Apr. 2013, p. 1326-1334. Michael D. Hurd, Paco Martorell, Adeline Delavande, Kathleen J. Mullen, Kenneth M Langa.
- 2014 Alzheimer's Disease Facts and Figures. Alzheimer's Association.
- Intellectual Disabilities. 2009 Dec;47(6):425-35. doi: 10.1352/1934-9556-47.6.425. Health profile of aging family caregivers supporting adults with intellectual and developmental disabilities at home. Yamaki K., et. al.
- Woods and Poole Economics, Inc., "2008 New England State Profile: State and County Projections to 2040"
- Alzheimer's and dementia in the oldest-old: a century of challenges. *Current Alzheimer's Research*. 2006 Dec; 3(5):411-9. Kawas CH, Corrada MM.
- Fact Sheet. Down Syndrome and Alzheimer's Disease. Alzheimer's Association. 2012.
- Miniño, A., Xu, J., Kochanek, K. & Tejada-Vera, B. (2009). Death in the United States, 2007. NCHS Data Brief, 26.
- Bigby, C. (2008). Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability, *Journal of Intellectual and Developmental Disability*, 33(1), 76-86.
- The MetLife Study of Caregiving Costs to Working Caregivers.
- Heller
- <http://bhpr.hrsa.gov/nursing/grants/phcastimplementationreport.pdf> Retrieved June 13, 2014.
- Dementia in the United States. *The New England Journal of Medicine*, v. 368, no. 14, Apr. 2013, p. 1326-1334. Michael D. Hurd, Paco Martorell, Adeline Delavande, Kathleen J. Mullen, Kenneth M Langa.
- NDSS, 2009
- Bittles et al., 2002
- Janicki, Dalton, Henderson, & Davidson, 1999
- Braddock, Hemp, & Rizzolo, 2008
- Lakin, Larson, Salmi, & Scott, 2009
- Janicki 2000
- Alvarez, 2008